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UNDERSTANDING AUTISM

A guide for parents
and professionals



**London Borough
of Hounslow**

Hounslow Educational Psychology Service

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Introduction

Finding out that your child – or a child you know or work with, is autistic may leave you with many questions about what autism is, what that means for them and how you can support them. Your preconceptions about what autism is may also be challenged, as your child may present in a very different way to other autistic people you know or have heard of.

An important thing to remember is that the diagnosis doesn't change who your child is – but it can give you an explanation for some of their needs and differences, and a framework for understanding and supporting them better. Another important thing to bear in mind is that autism isn't an illness or a disease; rather, it is a difference in how some people think, perceive the world and communicate.

Outdated ways of looking at autism sometimes focused on making autistic people conform to non-autistic standards, such as by demanding eye contact even if the child found that uncomfortable. This idea has now been rejected and it is recognised that we all need to be actively thinking about how we can support autistic people by adapting our communication styles, environments and classrooms, amongst others. In order to do that successfully, though, we first need to recognise that no two autistic people are the same and we need to understand each young person's unique set of strengths, differences and needs. Reading

this guide and answering the questions in it could be the first step of this journey.

We now know from research that the majority of autistic people prefer to use what we call identity-first language – or saying “autistic person” rather than “a person with autism”. Your autistic young person may have a different preference and that is perfectly fine, too.

This guide will introduce you to some of the key traits many autistic people have in common; however, as no two people are exactly the same, you are encouraged to reflect on how your autistic young person experiences those traits by answering the questions after each chapter. You can do this by discussing those with the young person, as well as based on your observations and knowledge of them. This will help create a truly personalised overview of their profile of strengths, needs and differences, beyond simplistic stereotypes.

How do I use the guide?

This guide can be used flexibly and you are welcome to dip in and out of it – there is no particular order in which the chapters need to be read and you are welcome to start with the topic that interests you or applies to the autistic young person you’re supporting the most. School staff and the child's parents are encouraged to meet and complete the relevant sections of the journal together, in order to

identify common themes as well as differences in their presentation at home and at school. Another way of completing the journal would be for a member of school staff or a family member to go over relevant sections of the young person's version of the guide with them and discuss the questions together. It is important that this information is then shared with the key people in the child's life so that they have a complete picture of their profile of strengths and needs. A list of who those people are and what information they would like to be shared should be drawn in collaboration with the young person.

The factual part of each chapter is meant to provide a brief – and hopefully accessible, overview of each key topic or term, rather than a detailed academic exploration of them. There are many excellent books and articles that have already done that, and references to those are included at the end, if you would like to find out more about them.

1. Masking/camouflaging

Some autistic people develop strategies and behaviours to fit in socially or to appear “less autistic”, and this is known as “masking” or “camouflaging”.

For example, they might be:

- Making eye contact even when this feels uncomfortable, in order to conform to social norms
- Rehearsing conversations and planning “scripts” for conversations and social interactions
- Trying to suppress their discomfort because of sensory overload (loud noises, bright lights, multiple conversations overlapping) in a social, school or work context, amongst others, which can leave them feeling exhausted
- Paying close attention to the behaviours, reactions, clothing styles or interests, amongst others, of neurotypical people, and trying to copy those

These are not necessarily behaviours or strategies that autistic people are using consciously or on purpose – some of those may have become intuitive to them after many years of “practice” and they may not realise that they’re masking. Masking can have an important protective and adaptive function that helps autistic people navigate a neurotypical world where people can be judged harshly

unless very specific social scripts are followed (for example, not smiling or making eye contact can be interpreted as “rude”, “bad manners” or as a sign of not listening).

Masking can be an exceptionally laborious process that can leave autistic people feeling exhausted and burnt out. They may find that they need time to recover after masking for longer periods of time (e.g. after school; after a big social event, such as a birthday party or a wedding) – this is sometimes informally referred to as “social hangover”, or altogether avoid situations where they need to mask. We are now beginning to understand the harmful impact of long-term masking on autistic people’s mental health, which wasn’t fully recognised previously.

Masking/camouflaging

Think about your autistic young person...

What are their key “masking” behaviours or strategies?

Are there any particular places, situations or contexts where they're more or less likely to mask?

More likely to mask	Less likely to mask

Are there any particular people around whom they mask more? Why do you/ they think that is?

Are there any particular people around whom they don't mask their autism? Why?

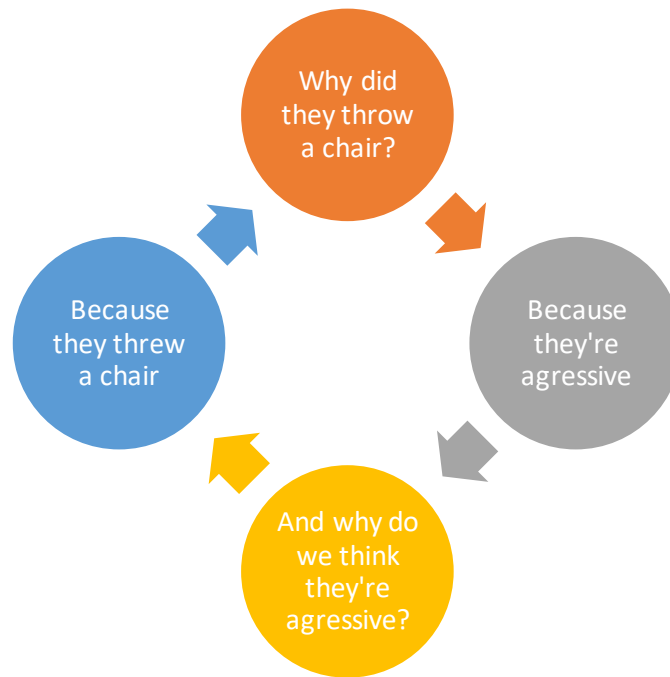
What impact does masking have on their mental health and general wellbeing?

2. Externalising vs internalising emotions

Some people are more likely to express their emotions and reactions in an overt, easy-to-notice way – in other words, they *externalise* their emotions. Others are more likely to keep their feelings in, or *internalise* them, meaning that they may appear calm when they are, in fact, in considerable distress. Most of us will do both, depending on the context, situation or who we are with.

Externalising

An example of externalising could be a teenager at school expressing their distress by throwing a chair – a reaction that is immediately obvious to those around them and one that is hard to ignore. It's important to bear in mind, though, that while *externalising* might seem to be more straightforward to interpret on the surface level, this isn't necessarily the case. In this particular example, the teenager's behaviour could be interpreted very literally, as a sign that they are disruptive, angry or aggressive. This interpretation, however, would tell us nothing about what led to the throwing of the chair. It will also likely lead us to meaningless, circular explanations:



If we look at behaviour as a form of communication, what the teenager may be trying to communicate could be their distress or discomfort. As such, the throwing of the chair may have been the end result of a long cycle of frustration and their needs not being met.

Externalising emotions and reactions could mean that their needs are identified early, however they may also be interpreted wrongly or in an overly simplistic, superficial manner.

Internalising

In contrast, someone who *internalises* would be less likely to show overt or immediately obvious signs of distress, and they would be more likely to direct their frustration, anger or disappointment *inwards*. This could also apply to

positive emotions, where a person feels intense joy, empathy, love or care but does not express those overtly.

Internalising is a particularly important concept to understand in autism, as some autistic people tend to internalise their difficulties, meaning that their needs may not be detected as early as the needs of autistic people who present with a more externalising profile and accompanying learning disabilities, for example. The “internalised presentation of autism”, which is prevalent across genders but appears to be more common in girls and women, can lead to delayed or inaccurate diagnosis, and lack of adequate support.

If they're autistic and they internalise their difficulties, they may appear very “calm and collected” on the surface level and those around them may not realise the extent to which they're struggling in certain situations. If they fit this profile, masking their discomfort for prolonged periods of time could lead to exhaustion and burnout, which, in turn, could result in mental health difficulties.

Some autistic people may internalise in specific contexts (school, most social situations) but externalise in the safer and more familiar environment of the home.

Consider the following very common scenario, which highlights the link between the internalised profile of autism, internalising and externalising in different contexts, and delayed diagnosis. Think about the young person's

time at school and whether you can spot any similarities to their experiences:

Ella presents as very quiet but diligent and studious at primary school; she is very well-behaved and has a small group of friends. However, as soon as she returns home, she is extremely exhausted and needs to lie down in her room for some time. Her parents say that she can have “intense” and “extreme” emotional reactions to what others perceive as minor situations at home, but which are very distressing for her, such as last minute changes of plans. School staff say that they don’t see any of those difficulties at school and query whether Ella’s parents would benefit from support with parenting.

When Ella starts secondary school, her needs become much more apparent at both home and school– she has been internalising her difficulties for years, however the changes and demands associated with being in secondary school, the more complex friendship dynamics, alongside the onset of puberty, have made masking even more exhausting and laborious. Ella is now highly anxious, including in relation to school attendance, which she finds overwhelming, and has panic attacks in the morning. She is first referred to Child and Adolescent Mental Health Services and is diagnosed with anxiety. She is offered support around “Emotionally Based School Non-Attendance”, however this is not effective and she continues to find going to school exceptionally challenging.

Her mother accidentally comes across an article about the internalised profile of autism and recognises many of the differences and difficulties she has observed in Ella. She is then referred for a neurodevelopmental assessment and, after being on a waiting list, is subsequently diagnosed with autism.

As we can see from this case study, it can take years for the needs of an autistic young person with an internalised presentation to be identified. If they fit this profile, they may have gone through their primary school years just about managing to “keep it together”, often by masking at the expense of their mental health. The difficulties of autistic people who internalise can then be seen as a mental health or even a behavioural issue, and they may accumulate a number of diagnoses that reflect some of their more pronounced needs (e.g., anxiety), or they may be given an entirely different and even inaccurate diagnosis (e.g., “emerging personality disorder”).

While the initial anxiety diagnosis in this case study wasn't necessarily wrong – Ella did indeed have very high and debilitating anxiety levels, this doesn't quite capture the full extent of her needs. Having a diagnosis – any diagnosis, can give those around her a false sense of security that the “cause” or source of her difficulties has finally been identified and that these can now be treated as a mental health condition. This is known as “diagnostic overshadowing” (they can find out more about it in

Chapter 18). This could also mean that, once a diagnosis has been given, no further questions are asked about other possible explanations.

In this case study, not realising that Ella is autistic could lead to inappropriate or exclusively “within-person” treatment plans that centre the “problem” within Ella and fail to consider how the environment at school could be modified so that it’s less overwhelming for her. Not having an explanation that fully captures all of Ella’s needs is also likely to make it harder for her to understand herself, her strengths and her needs, as her anxiety is the result of her unidentified and unsupported needs, rather than their cause.

Externalising vs internalising emotions

Think about your autistic young person...

Do they externalise or internalise their feelings more?

Where and when do they tend to internalise more? Why?

Can you think of any examples where they internalised their feelings or distress

At school	At home	In social situations

Where and when do they tend to externalise more? Why?

Are there any particular feelings that they tend to internalise more? Why?

Are there any particular feelings that they tend to externalise more? Why?

3. Autistic Burnout

Autistic burnout is a state of:

- extreme overwhelm
- longstanding exhaustion
- withdrawal
- difficulty functioning on a day-to-day basis

During an episode of burnout, autistic people may find that they are struggling with, or altogether avoiding, interacting with other people, social events and any other tasks that require putting on a “social mask”. They may also find that they struggle with motivation and starting activities, as well as planning and organisation (these are also called “executive functions” and they can find out more about them in Chapter 17).

Autistic burnout is different from other types of burnout, such as the one some people experience at work. It’s likely caused by the demands of living in a neurotypical (non-autistic) world, where they may need to mask their differences on a daily basis or experience sensory overload, for example. There are many possible causes of burnout and they will vary from individual to individual, however periods of intense pressure – or where they have to manage competing demands and mask their differences, could make them more vulnerable to burnout.

Autistic Burnout

Think about your autistic young person...

Have they experienced autistic burnout?

What caused it?

Was there anything that would have helped prevent it?

What and/or who helped them recover from it?

4. Special Interests and Monotropism

Special interests are areas of intense interest and fascination that many autistic people have. Contrary to how they're sometimes presented in popular culture, autistic special interests don't have to be particularly unusual or eccentric – they can be just about anything. It's the *focus* and *intensity* of the interest that makes it a special interest, rather than what it is.

Monotropism refers to some autistic people's tendency to focus strongly on one area of interest which captivates their attention, sometimes at the expense of others – and this can be particularly evident in the case of special interests, which can become all-encompassing.

While some autistic people's special interests may be more scientific (physics; astronomy; maths), factual (historical facts; timetables) or technological (computers; computer games), they don't have to be. Examples of less “unusual” but just as intense interests could include:

- Collecting objects of interest
- Researching and collecting factual information on topics they're passionate about - such as TV shows, actors, musicians, film or book characters...or even autism itself
- Books

- Fashion
- Animals
- Art
- Writing
- Theatre
- Sports

Their special interests can bring them immense joy and, for some autistic people, they can also become a sanctuary and an escape from the outside world, particularly when overwhelmed.

Special Interests

Think about your autistic young person...

What are their special interests?

Have their special interests changed over time?

How do they feel when they're engaging in their special interests?

What do they take out of their special interests? What do they bring to their life?

Do they enjoy sharing their special interests with other people, or prefer to enjoy them on their own? Why?

5. Autistic joy

Autistic joy is the feeling of intense enjoyment, happiness and satisfaction some autistic people find in experiences or activities that bring them immense fulfilment. While the exact reason for autistic joy will, of course, vary from one person to another, some examples include:

- Their special interests, hobbies or activities that they can get lost in because they're so invested in them
- Having their sensory needs met – for example, jumping on a trampoline, swimming or simply being in water, wearing a particular item of clothing that fits “just right” and is made of the right fabric
- Interaction with animals or people around whom they can be their authentic self, without the need to mask

Autistic joy

Think about your autistic young person...

What are the things in their life that bring them joy?

What does happiness look and feel like for them?

Who are the people (or animals!) in their life that bring them great joy and happiness? How do they make them feel?

6. Sensory Processing Differences

Many autistic people find that they process sensory information, such as hearing, sight, taste, smell, touch, texture, balance, movement and awareness of their own body in space, differently. In particular, they may find that they're *hypersensitive* (or have a heightened sensitivity) to some types of sensory information, and *hyposensitive* (have a reduced sensitivity) to others.

Sound and noise – they may find that loud noises and certain sounds are much harder to tolerate than others, and make them feel overwhelmed. These could be anything from several people talking at the same time, to the sound of someone chewing or high-pitched noises. For some people, it isn't the sound itself that is the issue, but the fact that they are not in control of the duration and volume – so, if they were the one making the sound, they would be able to tolerate it.

They may also find that they are hyposensitive to sound in some situations. For example, they may be hypersensitive to noise produced by other people, but at the same time, greatly enjoy loud music in their earphones.

Touch – again, they may experience certain types of touch as overwhelming and uncomfortable (being hugged or held) if they are hypersensitive to touch, or they might crave stimulation such as deep pressure on the skin, if they

are undersensitive. Similarly, they may find the feel of specific textures difficult to tolerate (e.g. certain types of fabric and how they feel against their skin); unusual textures (e.g. jelly; sand), could also evoke a strong sensory response in them - positive or negative, either of which could be overwhelming.

Taste – they may experience the taste of different foods very intensively, to an extent where it becomes overpowering and overwhelming and, because of that, they might prefer foods that have a relatively plain and predictable taste (e.g. biscuits; a specific brand of chicken nuggets). This could also be affected by the food's texture – while a cracker or a biscuit has a smooth and predictable texture, fruit and vegetables, for example, can vary considerably in both texture and consistency.

Smell - they may experience certain smells as particularly strong and overwhelming, including ones that they come across regularly in their day-to-day life (e.g. perfume, cooking, petrol). They could also be hyposensitive to smells, meaning that they seek out certain scents that they enjoy, as they may have a soothing effect on them

Sight - if they are hypersensitive, they may find bright, fluorescent or LED lights uncomfortable on a sensory level. If they are hyposensitive, they may also find certain types of light soothing and enjoyable to look at for extended periods of time (e.g. lava lamp-type light), lights that make patterns and colours

Vestibular (balance) – if they are hypersensitive, they may find any disruption to their balance uncomfortable and this could also lead to motion sickness and nausea. If, on the other hand, they are hyposensitive, they may actively seek out movement, and particularly enjoy activities like swings, trampolining and certain fairground rides. As always, these are not mutually exclusive – it is possible that an autistic person would greatly enjoy the motion or the physical sensation of movement when in a car, bus or train, but they may nevertheless experience motion sickness in some of those

Proprioception (awareness of their own body in space) – they may struggle to identify their body's position and distance from other people and objects, and they may find that they bump into things, knock objects over or find it difficult to judge how far they are from objects or other people. They might also seek out sensations that make them very aware of their body's position in space, such as leaning against a hard surface, deep pressure on their muscles, tight hugs and sleeping under a weighted blanket.

Hyperarousal – if they are overstimulated because they're in a very busy environment they're not in control of (e.g. on public transport or in crowded spaces) or because there has been an unexpected change to their usual routine – or for any other reason that could overwhelm them, they could become *hyperaroused*. That means that they could feel “on edge” and become particularly sensitive to sensory

overload and react more intensively to things that they may usually be able to tolerate. Their anxiety levels might increase when they're in a state of hyperarousal and they may need a quiet space, low in stimulation and demands of any kind, in order to feel calm, regulated and "themselves" again.

Hypoarousal – similarly to hyperarousal, hypoarousal is also caused by being overwhelmed by their environment. However, the key difference is that when they're hypoaroused, they may feel "flat" and as if they need to "switch off" from their surroundings. They may also find it harder to maintain their attention and focus on what is going on in their immediate environment.

Sensory Processing Differences

Think about your autistic young person...

What are they...

Hypersensitive (oversensitive) to	Hyposensitive (undersensitive) to

Do their sensory processing differences affect their diet and food choices?

What helps them manage their sensory processing differences?

Are there any particular places or environments that they find:

Soothing	Overwhelming

What makes they feel hyperaroused? Are there any particular situations or places where they feel “on edge”?

What makes they feel hypoaroused? Are there any particular situations or places where they become overwhelmed and want to “shut down”?

7. Sleep differences

Many autistic people have difficulties with sleep, or different sleep patterns. For examples, they may:

- Find it difficult to settle into a routine before bed, or “switch off” from the day properly – they might be going over events or conversations that happened during the day, or thinking about the following day
- Struggle to fall asleep or stay asleep during the night
- Have very specific routines around bedtime, such as the order in which they get ready, what their room and bed need to look like, as well as preferences in terms of the temperature and the light in the room
- Struggle to wake up in the morning and feel tired, sleepy and not fully awake during the day. This, in turn, could make it harder to concentrate during the day, make them more sensitive to sensory overwhelm and make masking more difficult

For some autistic people, the night is the main time when they feel alert and fully able to focus – this makes sense, considering that, in some ways, there is less potential for sensory overload at night. For example, it is likely to be much quieter, with less need for social interaction. Similarly, the lack of natural light and the ability to control the light inside can be a soothing experience if they are sensitive to bright light. For some people, all of these factors make nights much more appealing for work than

requires concentration, or even purely as a way of quietly enjoying the activities that they find soothing and help them regulate, without the risk sensory and social overload during the day.

Sleep differences

Think about your autistic young person...

Do they work better during the day or at night? Why?

What helps them fall asleep at night?

Do they have any difficulties around falling asleep or staying asleep? If so, what do they look like for them?

8. Interoception

Interoception refers to our ability to detect internal sensations in our bodies, such as:

- Hunger
- Thirst
- When we need to use the toilet
- Being too hot or too cold
- Pain

Some autistic people find that they have lower sensitivity to those internal signals. This could make it harder to recognise – and meet, some of their basic bodily needs. For example, they may find that they only become aware of hunger, thirst or needing to use the toilet when those signals have become very hard to ignore – e.g. when they are extremely hungry, dehydrated or desperate to use the toilet. This, in turn, could mean that they may feel uncomfortable or overwhelmed on a sensory level during the day, but they may not always be able to identify why.

If they have a higher sensitivity to internal bodily signals, they may be particularly aware of certain sensations, such as their stomach being full, changes in temperature or changes in their body during menstruation, amongst others. This could be overwhelming and very difficult to ignore; hyperawareness can be particularly distracting and they might feel “on edge”, uncomfortable and distracted.

Interoception

Think about your autistic young person...

Are there any particular internal bodily signals that they find hard to identify?

How does that affect them on a day-to-day basis?

Are there any internal bodily functions they find particularly hard to ignore?

How does that affect their daily life?

9. Prosopagnosia

Prosopagnosia or “face blindness” is a difference some (but not all) autistic people have around face recognition. It means that they may find it harder to remember and recognise faces of both new and familiar people in their life. They may look for specific, more distinguished facial features, rather than the face as a whole, as a way of remembering what a person they don't know very well looks like (e.g. eyes/lips shape, as well as hair colour and length).

If they already find some aspects of social communication challenging, struggling with face recognition could make making sense of other people's emotions harder and it could also mean that they feel more anxious in certain social situations, because they may struggle to connect people's face to the conversations they've had – or remember who they have already met or spoken to.

Prosopagnosia

Think about your autistic young person...

Do they have any difficulties recognising or remembering faces? If so, does this apply to familiar, unfamiliar faces, or both?

What helps them recognise people's faces? Are there any particular strategies that they use?

How do they think this difference affects them and their day-to-day life?

10. Routines, structure and predictability

Having a clear sense of structure, predictability and order is an important part of many autistic people's lives. Routines can be one crucial way of managing the anxiety they may feel in situations where they have limited control, or where there is a lot of uncertainty and changes (such as in the context of education).

There are many different ways of establishing routines – those can be anything from wanting to know exactly what they need to do, step by step, when they have been given a task, to having a preferred route to the shops/work/their nearest bus stop. Autistic people may also have specific routines in terms of how they manage their time and social relationships. For example, they might like to meet certain people for specific activities, in groups or at particular times of the week. They may also have routines in terms of the order in which they do certain activities in their day-to-day life, as well as how they organise specific rooms in their home, and how their belongings are positioned in a space.

This is likely to give them a sense of control, order and stability, which can be grounding and necessary in an unpredictable and uncertain world, where the needs of autistic people are often not reflected.

Routines, structure and predictability

Think about your autistic young person...

Are there any particular routines or “rituals” they follow regularly? What do they do for them?

Routine	Positives	Drawbacks

Are there any particular places or situations where they need more structure? Why?

How do they respond to unexpected changes or disruptions to plans? What makes it easier to cope with those?

11. Anxiety

Anxiety is very common amongst autistic people – the fact that it is so common does, however, mean that its impact on autistic people’s wellbeing and daily lives is greatly underestimated.

Anxiety can take many different forms – while the underlying feeling may be one of worry and feeling “on edge”, the way it’s experienced by different people varies considerably. For example, in some people, it’s a very physical sensation such as a stomachache; for others – a general feeling of worry and as though something is about to go wrong imminently. Anxiety can also be an almost constant presence in some people’s lives, where they think about all possible scenarios that may go wrong in a given situation.

It’s important to remember, however, that autistic people’s anxiety levels could also increase due to:

- Sensory overload
- Continuous masking in social situations – or the pressure of “performing” socially and trying to figure out other people’s intentions, implied meaning in conversations or social dynamics
- Lack of, or disruption to, routines or previously agreed plans

- Being given unclear instructions or instructions with multiple steps

As a result, they may find that they:

- Avoid anxiety-provoking situations
- Adopt repetitive behaviours that give them a sense of control
- Stick to similar activities or familiar environments, places or people to maintain a degree of control and regulate their anxiety

We also need to bear in mind that anxiety doesn't have to "look" a certain way – while some people would go quiet and try to "blend into the background" to avoid attracting attention to themselves, others may find that they talk excessively when they're anxious, or that they react in a more intense, impulsive or irritable way than they normally would (or a mixture of all of these, depending on the situation). When overwhelmed, anxiety can also come across as anger or irritability.

Anxiety

Think about your autistic young person...

What does anxiety look and feel like for them?

What do they tend to feel, think and do when they're anxious?

Feel	Think	Do

Are there any particular situations, places or people around whom they tend to feel more anxious? Why?

Situations	Places	People

What are the things that help soothe and settle them when they're anxious? Is there anything that they have tried that wasn't as helpful?

Helpful	Not so helpful

What are some of the things others can do to support them when they're anxious? Are there things that are definitely not helpful?

Helpful	Not so helpful

12. Hyperempathy

One of the biggest, and perhaps most harmful, misconceptions about autism is that autistic people aren't empathetic. Rather than being lacking in empathy, *some* autistic people can express their empathy or concern in different ways (as is also the case for many non-autistic people), such as, by trying to help practically, thinking about the problem the other person is experiencing or by offering help and comfort in more physical way (e.g. making a drink).

Some autistic people are not only empathetic, but they also experience an intense, even overwhelming degree of empathy that is referred to as *hyperempathy*. If they are hyperempathetic, they may find that they feel for other people, animals or even fictional characters in books and films so profoundly, that they almost experience their emotions as their own. The intensity of the feeling can be overpowering, to an extent where they think about the person/animal/character/news story regularly, which can be very exhausting and overwhelming.

Hyperempathy

Think about your autistic young person...

Do they experience hyperempathy and, if so, in what situations?

What does hyperempathy feel and look like for them?

Are there any challenges they experience when they're hyperempathetic towards something or someone?

13. Social communication differences

While we know that many autistic people have social communication differences, the exact nature of those differences varies considerably from one person to another. Depending on their individual profile, they may find that they have differences or difficulties with:

- Proactive social communication, such as initiating conversations and participating in “small talk”
- Understanding implied meaning – something that hasn’t been said directly but is heavily implied and can be deducted from the context, tone, intonation or facial expression of the speaker
- Taking turns in conversations – they may find that they find it easier to either stay relatively quiet or to talk about a topic of interest to them
- “Social hangover” – they may need to recover for a certain period of time after intense social interaction and masking (for example, needing a day at home, with little to no communication with people, after attending a wedding, a party or a busy day at school)
- Understanding non-verbal communication, such as facial expressions, intonation and tone of voice
- Imagining how another person might act in a given situation based on past experience and behaviour –

however, it is also possible that if they're very good at spotting patterns, they can also identify patterns in other people's behaviour very well

- Making or maintaining eye contact – again, this varies considerably from one person to another. While some autistic people are comfortable with eye contact, others are more comfortable only making fleeting eye contact or avoiding eye contact where possible

Social communication differences

Think about you autistic young person...

What are the key areas of social communication they find challenging?

Are there any specific contexts or situations that are particularly stressful or difficult for them to navigate socially?

Do they need to recover after periods of intense social interaction (at school or special events such as birthday parties or weddings)? If so, what do they tend to find helpful?

14. Alexithymia

Some studies have estimated that **85% of autistic people** experience *alexithymia* (pronounced ah-lexi-thai-meeah)- or a difficulty with recognising and naming their emotions. While they may be perfectly capable of describing various emotions and what they mean verbally (using words), they may nevertheless struggle to identify them within themselves or to distinguish between them.

For example, while some autistic people are able to define the word “anxious”, they may not be able to recognise their own anxiety or easily distinguish it from being overwhelmed, frustrated or irritated. This could make it particularly difficult to monitor for triggers that may lead to anxiety or overwhelm; similarly, it could also mean that some therapeutic approaches that rely on being able to recognise their own emotions and identify triggers have to be adapted.

Alexithymia

Think about your autistic young person...

Do they experience alexithymia and, if so, are there any particular emotions they find more challenging to identify?

How does alexithymia affect them in their day-to-day life?

15. Strong sense of justice and fairness

Fairness, honesty and equality can be particularly important for autistic people and they may find that their strong sense of right and wrong is a key guiding force in all aspects of their life – from how they choose their friends and partners, to their career choices and special interests.

They may also find it extremely difficult to tolerate injustices of any kind, as well as inconsistent rules that only apply to some people. This can be particularly challenging in an educational context, where they're often expected to conform to social norms and not challenge established rules. Autistic people can find this particularly difficult and this can sometimes be (wrongly) interpreted as being defiant or oppositional.

Strong sense of justice and fairness

Think about your autistic young person...

Are there any causes, social issues, rules or injustices that they care particularly strongly about?

What are the most important values or principles they stand for?

16. Autistic inertia

Autistic inertia is the difficulty some autistic people have with both initiating, or starting, new tasks and activities, and stopping them. This could also mean that they:

- Find it difficult to start new tasks and it may seem as though they “procrastinate” regularly
- Find transitions from one task or activity to another difficult because they have to stop what they are doing and start again
- Become stuck if they come across a difficulty or something that they are not able to address or resolve immediately, and struggle to move past it
- Struggle to return to a task or an activity after interruptions

Autistic inertia can also be linked to differences with executive functioning, which we will explore in the next chapter.

Autistic inertia

Think about your autistic young person...

If they experience autistic inertia, are there any particular tasks or activities that they find harder to start and stop?

Are there any strategies that they have found helpful in managing inertia?

17. Executive functioning

Executive functioning refers to the skills we need to complete complex tasks and activities, and includes:

- Planning and organisation
- Focus and attention
- Task initiation (starting a new activity without being prompted)
- Working memory (the ability to remember information for short periods of time while completing another task with that information; such as mental maths, copying notes from a board)
- Self-regulation (the ability to control their impulses and emotional reactions)
- Time management
- Metacognition (the ability to think about thinking and learning)
- Thinking flexibly

Some studies have estimated that a significant proportion of autistic people (up to 80%) have difficulties with executive functioning. This could mean that they may struggle with getting themselves organised, planning day-to-day tasks (even seemingly simple everyday tasks such as showering or getting dressed require quite a lot of planning), keeping track of deadlines and staying focused.

Executive functioning

Think about your autistic young person...

Which aspects of executive functioning do they find challenging, if any?

Have those challenges got better, worse or stayed the same over time? Consider each area of executive functioning they struggle with

Which of the strategies they have tried are helpful and which ones, not so helpful?

Helpful	Not so helpful

How do their executive functioning difficulties affect their life?

18. Diagnostic overshadowing

Diagnostic overshadowing happens when all the differences and difficulties a person experiences are attributed to one primary diagnosis, without considering other explanations or diagnoses. For example, as described in Chapter 2, an autistic person who masks their differences and has high anxiety levels as a result may initially be diagnosed with anxiety. While this may not be an inaccurate diagnosis, it does not offer a complete picture of their needs, however all of their subsequent difficulties may be attributed to the anxiety – without considering that they might, in fact, be autistic.

This could also mean that some autistic people don't have access to the support they need in education, at work or in society, because their needs are not fully recognised.

Diagnostic overshadowing

Think about your autistic young person...

Have they experienced diagnostic overshadowing? If so, how and why do you think it happened?

How has that affected their experiences of school/education, accessing support and their life more generally?

19. Autistic meltdowns

When autistic people are overwhelmed due to sensory or emotional overload, a sudden change of plans or masking for an extended period of time, they may experience what is sometimes called an *autistic meltdown*.

Meltdowns can feel like very intense reactions that are outside of the autistic person's control, where they may say or do things that are out of character (e.g. they might throw objects in frustration, or express their distress by shouting). They might feel embarrassed or as if they have lost control after a meltdown – but remember, meltdowns are *not* tantrums or being deliberately “difficult” or aggressive. They are a stress response and a sign that something in the autistic person's environment has overwhelmed them, and needs to change.

Autistic meltdowns

Think about your autistic young person...

Have they had an autistic meltdown? If so, when did it happen – or, if they happen regularly, when do they tend to happen?

Where	When	Triggers

What does a meltdown feel and look like for them?

What helps them regulate after a meltdown?

20. Autistic shutdowns

Shutdowns are often caused by the same triggers as meltdowns (see Chapter 19); however, rather than *externalising* their reaction – or expressing it physically and openly, the autistic person might find that they “freeze” and instead “switch off” from their surroundings that are overwhelming them. This can take many different forms:

- They may find having conversations with people very difficult during a shutdown and may go silent or very quiet
- They may find that they crave stillness and predictability, but some people also make repetitive sounds or movements when overwhelmed
- They may seek the familiarity and solitude of familiar surroundings, such as their room, and “isolate” there until they feel regulated again

Often, a shutdown is the body’s way of telling the autistic person that they are overwhelmed – as with meltdowns, this is usually a sign that something in their environment isn’t meeting their needs and has to change.

Autistic shutdowns

Think about your autistic young person...

Have they had an autistic shutdown? If so, when did it happen – or, if they happen regularly, when do they tend to happen?

Where	When	Triggers

What does a shutdown feel and look like for them?

What helps them regulate after a shutdown?

Recommended reading and resources

- Being Autistic (And What That Actually Means) by Niamh Garvey
- So, I'm Autistic: An Introduction to Autism for Young Adults and Late Teens by Sarah O'Brien
- Nurturing Your Autistic Young Person: A Parent's Handbook to Supporting Newly Diagnosed Teens and Pre-Teens by Cathy Wassell
- Can't Not Won't: A Story About A Child Who Couldn't Go To School by Eliza Fricker
- When the Naughty Step Makes Things Worse: Parenting for Children (and Adults) Who Need Something Different by Dr Naomi Fisher and Eliza Fricker
- Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing by Dr Luke Beardon
- School Wellbeing Risk and Resilience Card Set by Dr Jerricah Holder
- The Amazing Autistic Brain Cards by Dr Gloria Dura-Vila

The author of the present publication has also written a book on autism and girls, published by Jessica Kingsley Publishers:

- Under the Radar: An Essential Guide to Autism and Girls by Dr Emilia Misheva

This guide is made freely available - if you have used it, your feedback would be greatly appreciated:

"Understanding Autism" Guide feedback

